



Emergency care patient driven solutions for severe asthma

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Keywords:	asthma, soft systems methodology, Quality improvement, systems thinking, emergency

Figure 1 An overview of soft systems methodology Checkland’s 7 stage overview

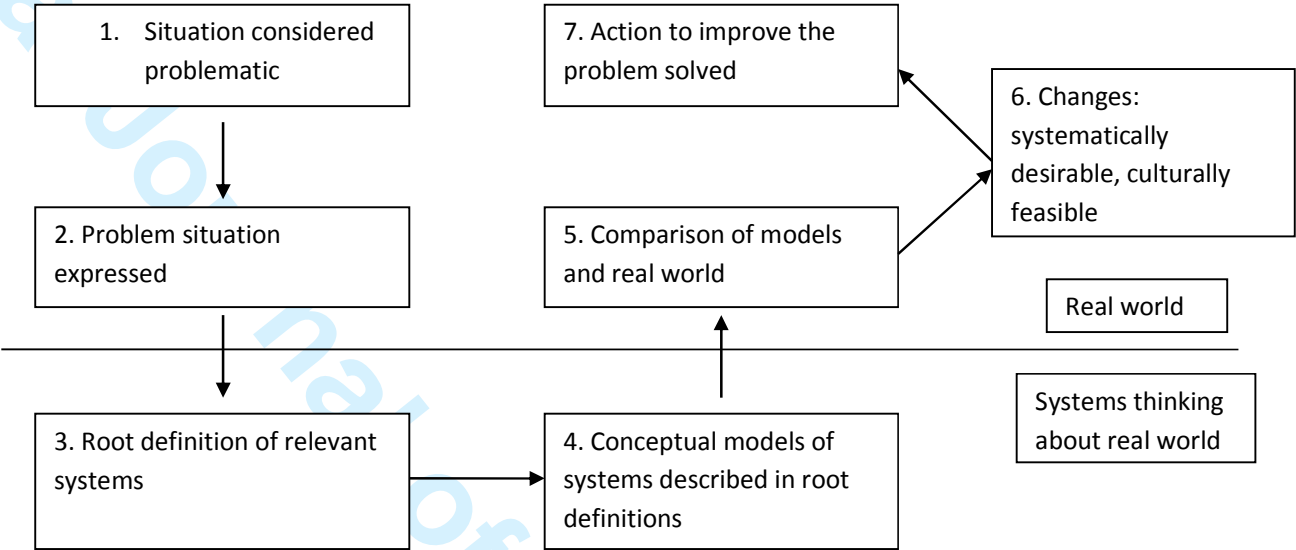
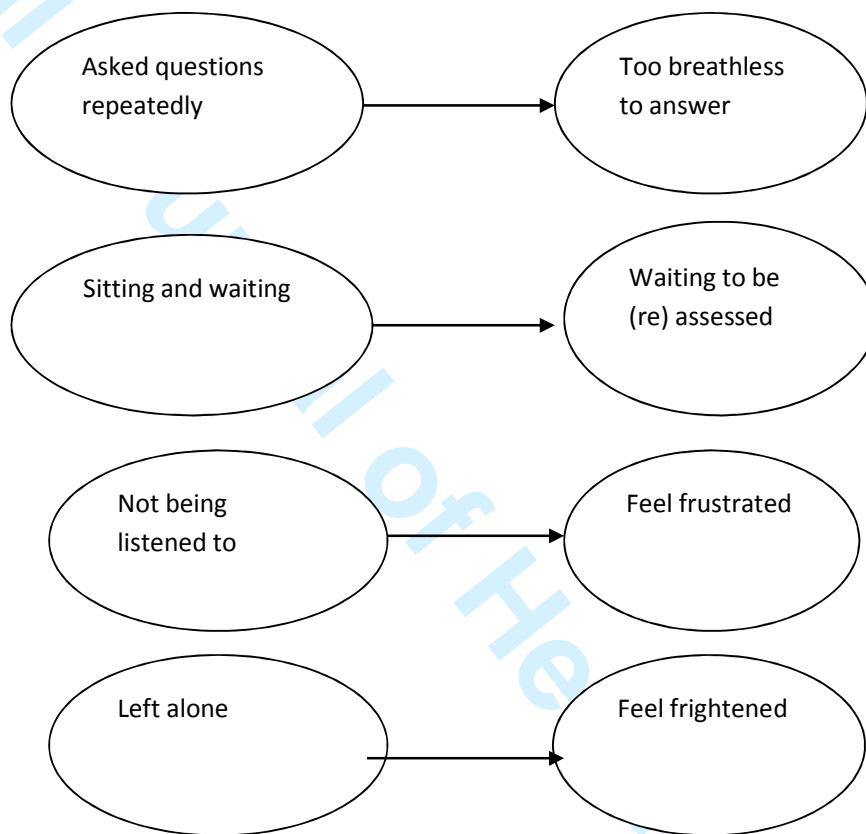


Figure 2 Conceptual model of the reasons why the 'severe' asthma patients were not going to ED when they needed to.



I have brittle asthma. Please direct me straight to the resuscitation unit. I may be unable to talk/answer your questions. Please see below:

Contact details:

Name _____

Date of birth _____ Age _____ NHS number _____

Address _____

Telephone _____

Next of kin _____

Relationship _____ Telephone _____

GP Practice _____

GP's name _____ Telephone _____

Consultant's name _____

Triggers: _____

Best peak flow/FEV1 reading: _____

If I need an arterial blood gas please: _____

My signs and symptoms in an asthma emergency:

- _____
- _____
- _____
- _____

What has worked previously:

- _____
- _____
- _____

Drug allergy/Adverse reaction: _____

Pre-hospital treatment: _____

Previous admissions:

ITU:	Y / N	Date
with intubation:	Y / N	Date
HDU:	Y / N	Date

This asthma passport was agreed by me

and _____

on _____

Review date _____

This asthma passport is intended as a guide only. Always use clinical judgement and maintain patients privacy and dignity.

The silent asthmatic is an asthmatic in trouble

A systems thinking approach to understanding barriers to seeking medical care during severe asthma and possible patient driven solutions.

Abstract

Purpose: Patients with severe asthma were choosing not to use the emergency department in extremis and were self-medicating when experiencing severe asthma, putting their lives at risk. This local issue reflected a nationwide situation. The aim of this study was to better understand the reasons for this locally and consider practical solutions in a structured way with users of the service

Design/Methodology/approach: Systems thinking was used (soft systems methodology) to better understand the problem and examine possible solutions in co-production with people who live with severe asthma.

Findings: The problem was identified and fully revealed-patients felt vulnerable and fearful of the emergency department. This appeared to be a well-defined problem with possible solutions. Once this tame problem was revealed a possible solution was developed in co-production with patients. The solution was an Asthma Patient Passport (APP) which increased confidence in patient's ability to communicate their needs in severe distress by facilitating communication of needs and decreased the work patients had to do to achieve care from twelve steps to five steps. The implementation of the APP is currently being evaluated.

Originality/Value: By revisiting systems thinking and identifying problems, a solution was possible. Although methods such as soft systems methodology have limitations when used to in wicked problems, such methods still appear to have merit in tame problems and could be used in these circumstances to fully understand problems and design practical solutions.

Keywords: Asthma, Emergency, Systems Thinking, Soft System Methodology, Patient Passport

Article Classification: Case study

Background

Approximately 1,200 people with asthma die in the UK each year and 90% of these deaths are preventable (Asthma UK, 2014). The UK has a higher death rate from asthma than other similar countries and numbers have not reduced significantly in recent years (Levy *et al.*, 2014). The *Why Asthma Still Kills: The National Review of Asthma Deaths (NRAD) Confidential Enquiry Report* was published in 2014 (Royal College of Physicians, 2014). Its aim was to identify avoidable factors and make recommendations for implementing changes to improve care and to reduce the number of deaths from asthma in the future. NRAD concluded that there are factors associated with the disease, the medical management and the patient's behaviour or psychosocial status which contribute to death. Most deaths occurred before admission to hospital and most patients who died of asthma had chronically severe asthma (British Thoracic Society, 2014).

Local context

In conjunction with NHS Improvement, some work was undertaken around asthma re-attendance in the Emergency Department (ED) at one large London NHS Foundation trust during 2010-2011. A local initiative in the form of an audit cycle using increased general practitioner (GP) and General Practice Nurse (GPN) communication, formation with patients of an action plan and an emergency department pro forma for emergency care was initiated over a year. As part of the initiative the Trust patient experience team facilitated a piece of work which was to elicit reasons for re-attendance. This initial improvement project yielded a decrease in 30day asthma re-attendance of 45% (75 patients re-attended 143 times between

May 2010 and April 2011, out of a total of 888 adult attendances) and of admissions by 60%. Reducing asthma re/attendance and admissions is an indicator of better asthma control and quality of life (British Thoracic Society, 2014).

The ‘severe’ asthma patients were excluded from the scope of the original NHS Improvement work because it appeared that they had different needs. Asthma is known as ‘severe’ when a patient has a confirmed diagnosis of asthma and ongoing symptoms despite adherence to treatment. It is recognised by one or more episodes of previous near-fatal asthma, e.g. previous ventilation or respiratory acidosis, previous admission for asthma especially if in the last year, requiring three or more classes of asthma medication, heavy use of β_2 agonist and repeated attendances at ED for asthma care especially if in the last year (British Thoracic Society, 2014).

The patients at the Trust with ‘severe’ asthma are fully medically optimised and have the ongoing support of the specialist asthma clinic. They all have bespoke asthma action plans, which are drawn up between themselves and the Asthma Clinical Nurse Specialist (CNS). The plan outlines how to titrate asthma treatments according to symptom and when to access medical assistance.

To evaluate these plans locally interviews were conducted with patients who were using the plans. The interviews revealed patients valued the asthma action plan but there was usually awkwardness around when and how to access emergency medical care. On exploring this a theme emerged that the patients were putting their lives at risk because they had such a difficult time in ED and they preferred to stay at home and take high doses of bronchodilator therapy. Patients said they avoided the ED even in extreme respiratory distress for a number of reasons. These were: feeling of vulnerability or fear in the emergency department, when they are least able to talk they are unable to say what they need which causes more distress, they are asked the same questions many times, they feel that they are not always listened to and that treatment isn’t always escalated as quickly as they feel it needs to be. In addition, patients had no choice as to which ED the ambulance service took them and they would therefore elect to use either their own or public transport even when in severe respiratory distress. This understanding of this experience provided the basis of problem construction and therefore this study.

A soft systems thinking approach (Checkland, 2001) was taken to try to identify the specific problem and then construct a satisfactory and sustainable solution to the problem. Soft Systems Methodology (SSM) was chosen as it helps conceptualise, define and address problems and is particularly useful in people oriented systems and allows the consideration of an issue from a more holistic whole systems perspective. Once a potential set of possible solutions had been identified a “Plan, do, study, act” (PDSA) cycle was used as a quality improvement approach (Langley *et al.*, 2009).

Methods

To gain a fuller understanding of the problem as a concept soft system methodology (SSM) was applied (Langley *et al.*, 2009; Checkland 1981). An overview of this can be seen in Figure 1. SSM originated in systems engineering and has been in use for over thirty years. Whilst it is commonly considered that General Systems Thinking has not delivered the anticipated changes in healthcare, the application of systems thinking to tame problems has been beneficial in many areas (Checkland, 2001)

Insert Figure 1 here.

Results

Identifying the problem locally

Step 1: Situation considered problematic

From the previously conducted local interviews patients with 'severe' asthma did not appear to be seeking emergency medical help when they needed to. This behaviour is associated with avoidable harm/death (Levy *et al.*, 2014). The NRAD report into avoidable asthma deaths (British Thoracic Society, 2014) states that 45% (87) of the 195 people who died did so without seeking medical help or before emergency medical care could be provided. There was a history of previous hospital admission for asthma in 47% (90 of 190). Nineteen (10%) of the 195 died, within 28 days of discharge from hospital after treatment for asthma. At least 40 (21%) of the 195 people who died had attended a hospital emergency department with asthma at least once in the previous year and, of these, 23 had attended twice or more. 39% appeared to have 'severe' asthma. The NRAD report (British Thoracic Society, 2014) and local patient experience work underlined the importance of having a personal asthma action plan. The fact that during the process of co-creating an asthma action plan the asthma CNS often felt a resistance from the 'severe' asthma patients around when and how to access emergency medical care needed exploring. In discussing this with the patients, the asthma CNS became aware that the patients were putting their lives at risk because they had such a difficult time in ED, and that as a result of this difficult time in the ED they preferred to stay at home and take high doses of bronchodilator therapy. Similar findings had been reported before (Asthma UK, 2004) but the reasons behind this had not been considered in a systematic way within this service. The Trust currently cares for around 800 "severe" asthma patients per year. Defining the problem revealed that it had the characteristics of a tame problem (Rittel and Webber, 1973) in that the problem can be clearly articulated with a clearly desired outcome-that patient in distress feel able to go to the emergency department. The problem can be stated as a gap between what is and what 'ought' to be and this was agreed up by professionals and patients.

Step2: Problem situation described

SSM helps formulate and structure thinking about problems in complex human situations. It does this by applying systems thinking about things that happen in the real world. It is most usefully carried out by the people involved in the problem situation, in this case people with 'severe' asthma along with the asthma CNS who provided expert help to guide and facilitate the process. The asthma CNS facilitated a focus group with the patients and the allergy CNS to gain a situational insight. The findings from the group echoed the same themes of the asthma plan evaluation (Box 1).

Box 1: The emerging themes from focus groups around why patients with 'severe' asthma do not want to go to the ED.

- Feeling vulnerable and afraid
- When least able to talk asked the same questions repeatedly
- When least able to talk, they are unable to say what they need
- They feel that they are not always listened to
- Life-saving treatments aren't always escalated as quickly as necessary
- Healthcare staff do not always appreciate the severity of the attack
- Individual fears, such as being left alone in a cubicle when they think they are dying

Owing to the initial meeting process mapping was introduced to explore some of the issues (Newell *et al.*, 2014). The process mapping revealed that twelve separate actions were required to gain treatment in self-presentation to the ED and thirteen if brought in by ambulance (Newell *et al.*, 2015)

Step 3: Root definitions

It was agreed by the co-production group that “*something needed to be done...*” thus a project team was established to set out a shared purpose and vision. The aim of the project was that patients with ‘severe’ asthma would seek emergency help appropriately. A further objective was that when patients with asthma went to the ED they felt they were being taken seriously and could work in partnership with staff to achieve the best outcome for themselves. Returning to SSM to help achieve this objective several questions are posed.

1. What the system will do?
2. How it is done?
3. Why it is being done (long term aim)?

Underpinning this is a transformation process in which something is changed or transformed into something else. This revealed the study question/system requirement: *A system to encourage people with ‘severe’ asthma to go to the Emergency Department when they need to, in order to get the right treatment, in the right place, at the right time without fear (outcomes).*

Once the problem has been defined the SSM CATWOE checklist (Checkland 2001) was used to form an approach to the problem and consider possible solutions.

Customers - it was the duty of the asthma CNS to listen carefully to what the patients with severe asthma had to say about seeking emergency help and contribute to enabling ED and London Ambulance Service (LAS) staff to understand patients’ needs.

Actors - those involved in the situation and in partnership with them, to act on what had been discussed. How might they react? What in their stake?

Transformation - so that the patient group would change their behaviour and go to ED when they needed to. Staff reacted in a way that reassured and met patients’ needs rather than increase distress and fear.

Weltanschauung (this is the right thing to do) - because not to do so put patients at risk - they say they are already at risk and want to do something about it.

Owners of the process - all the stakeholders and included: patients with ‘severe’ asthma, ED clinical staff, ED reception staff, LAS staff, the asthma Professor, the Patient Experience Team, Communications and Patient Publications.

Environmental constraints - NRAD (British Thoracic Society, 2014) describes how people with asthma were needlessly dying because patients failed to recognise the severity of the asthma attack, failure of healthcare staff to recognise attack severity and inappropriate or under-treatment. It was fundamental that any plan took this into account.

Step 4: Conceptual models of systems described in root definitions

Drawing out a conceptual model highlights the many reasons why the patient group weren’t going to ED without losing sight of how the component parts fit together (Figure 2).

Insert Figure 2 here

Designing the intervention-the Concept of the Asthma Patient Passport (APP)

This group of patients aren't necessarily local to the Trust and therefore need to use different EDs and so a local arrangement wasn't an obvious solution. Another option was to have a national database of all those people with 'severe difficult to manage asthma' so that the ambulance service and the various UK EDs had all the necessary information about the patient but this was impractical. The establishment of such a system would be resource intensive at this time as there is no common information technology infrastructure in the UK. Other long-term condition groups, such as people with learning difficulties and people with mental health problems and palliative care needs, were already using a Patient Passport as a collaborative communication tool and this had been found to be helpful in accessing services (Abbot *et al.*, 2015). A local Chronic Obstructive Pulmonary Disease (COPD) Passport was being used and it was felt that the design had been well evaluated. The COPD Passport is a credit card sized z-card and is a simple record of relevant demographic and clinical information. Where the Asthma Patient Passport (APP) would differ from the COPD Passport is that it would be designed by patients for patients and would also consider both the needs of ambulance service and the various ED's. The other important factor was the decision to use the model for improvement as a way for implementing change in health services (NHS Institute for Improvement, 2014). Every time one of the patients used the APP the experience of using it was fed back by the patient or other user for example the LAS to the group and any improvements suggested incorporated into the APP. This proved to be a valuable way of winning commitment from the various health staff groups and the patients themselves.

Box 2 Suggestions that were incorporated into the Asthma Patient Passport design

- Putting the emergency information at the beginning of the document
- Adding a box for the Asthma Physician's signature to lend credibility
- Changing the word 'severe' to 'brittle' as it is more commonly understood in those who do not specialise in the treatment of asthma
- Having an explicit statement about what to do if arterial blood gases (ABG) are needed (as ED staff felt that gaining permission to undertake ABG's can be challenging at times)
- Adding a review date
- Having a section for pre-hospital treatment for the ambulance part of the journey
- Highlighting and dating previous ITU/HDU admissions
- Adding a 'triggers' section
- Designing watermarks that provide subliminal awareness information on crucial safety factor such as the silent asthmatic

Step 5: Comparison of models with the real world

The problem was examined the development of the APP to compare this model with the real world. The APP made the patient journey through the ED more efficient. Patients brought in by ambulance went through a 13-stage process before the APP was introduced. With the APP in place, there are now only nine steps. Self-presenting patients also went through 12 steps before the APP was introduced and five afterwards. The APP has streamlined the process by improving communication allowing improved access and flow through emergency care. This meant a reduction in delays and ensuring treatment is individualised and right the first time, thereby improving quality and possibly lowering costs (Newell *et al.*, 2015).

Step 6: Changes - systematically desirable, culturally feasible?

Does the solution work?

The APP was developed and piloted for three months with 15 patients. During this period it was used 15 times by seven patients. After a positive feedback and some minor alterations

based on the feedback the APP was trialled for one year. During this time regular meetings and consultations were held with all partners in care (patients, specialist nurses, ED staff, LAS staff and the medical consultant) who were consulted extensively throughout the trial period using this approach. Finally, an APP document (Figure 3) was devised that provided this patient group with the confidence to attend ED when appropriate, and assisted healthcare staff in treating them (Newell *et al.*, 2014).

Insert Figure 3 here

Is it worthwhile?

The APP addressed the 4 key areas most important to patients (being left alone, being unable to communicate needs, feeling frustrated at not being listened to, being asked the assessment questions repeatedly at a time when they are too breathless to talk) and in doing so improving; timeliness of treatment, decision making, patient experience as per the original aims of developing the APP (Newell *et al.*, 2014). The APP also appeared to meet a staff need captured in this comment ... *the patient doesn't have the pressure of having to give their story to the ambulance crew (which) takes the pressure out of the situation.* London Ambulance Service

Does the solution achieve its goals?

As patients have a better experience, they report that they are more likely to access emergency services in a timely manner and receive correct treatment (Newell *et al.*, 2014). It is now part of regular part of clinical practice at the London NHS Foundation trust of origin.

Step 7: Action to improve the problem situation

The action taken was to implement the APP for patients with 'severe' asthma at one large London NHS Foundation trust. There are plans to undertake a multi-centre study using a mixed-methods approach which will include an impact evaluation.

Discussion

There is both breadth and value in the SSM approach and the PDSA cycle in tame problems- that is problems that are well defined. Patient passports are in common use in other long term conditions (National Quality Forum, 2015). The APP was specifically co-designed to meet an expressed need and it was the patients, alongside the asthma CNS, that drove the development process. The core group consisted of the patients, the asthma CNS and the allergy CNS, and it was the collaborative approach adopted by the patients and the wider team (including ambulance and ED staff) that helped to get it right. Inextricably connected with this was the 'learning by doing' so that every time one of the patients used the APP it was discussed with the asthma CNS and the APP was improved. The tame problem was that 'severe' asthma patients weren't accessing emergency healthcare when they needed to. The patient's perspective is highly relevant to efforts to improve the quality and effectiveness of health care (Frew *et al.*, 2011) and because all parties were involved in the creation process, all parties benefited. There is a 'win, win, win' for the patients, the clinicians and the healthcare system. The patients feel more secure and are more likely to go to the ED and get the right treatment, in the right place, at the right time. Healthcare staff has all the necessary information which is individualised and easy to follow. The healthcare provider benefits because the process is leaner in terms of outcome. This might potential indicate a cost saving but this was not assessed during the study. The implementation of the APP is undergoing evaluation.

Conclusion

Systems thinking and SSM have been used in the past but with limited applicability. This may be because this methodology has been applied to “wicked” problems-these are problems that are complex and have no one answer. This work has shown that there is some benefit to be gained from the application of SSM in tame, well defined problems to help understand the problem and construct a solution.

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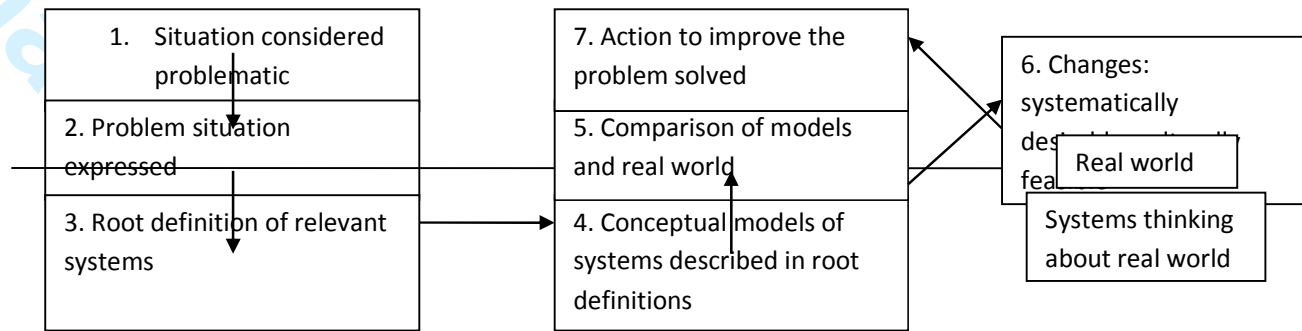
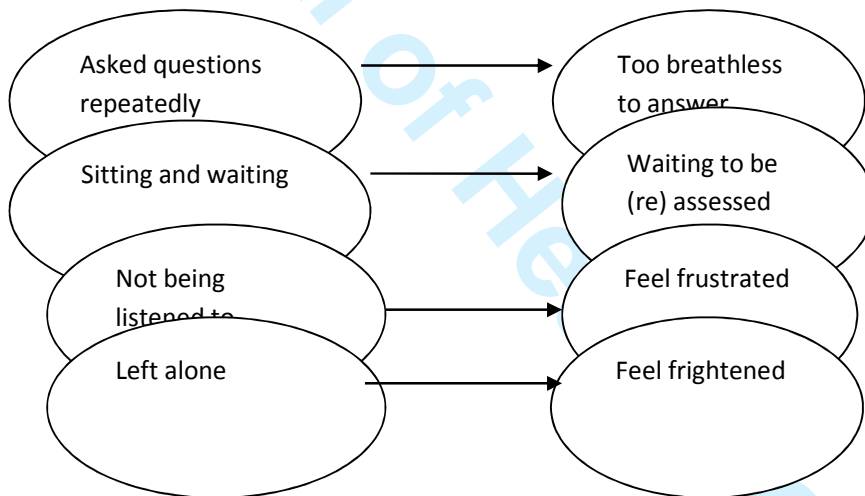
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Figure 3: The Asthma Patient Passport

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Date of birth

Address

Next of kin

Relationship

GP Practice

GP's name

Consultant's name

NHS number

Telephone

Telephone

Telephone

Drug allergy/Adverse reaction:

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A systems thinking approach to understanding barriers to seeking medical care during severe asthma and possible patient driven solutions
Emergency care Ppatient driven solutions for severe asthma for asthmatics needing emergency care

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Abstract

Purpose: Patients with severe asthma were choosing not to use the emergency department (ED) in extremis and were self-medicating when experiencing severe asthma, putting their lives at risk. This local issue reflected a nationwide situation. Our aim ~~—therefore—~~ was to better understand the reasons ~~behind for this~~ reluctance to attend the EDlocally and consider practical solutions in a structured way ~~—with users of the service~~

Design/Methodology/approach: Systems thinking (soft systems methodology) was used to ~~better understand the problem and~~ examine the issues resulting in this reluctance to attend the ED ~~possible solutions in co-production with people who live with severe asthma. Once this tame problem was revealed, a potential possible solution was developed in co-production with patients.~~

Findings: ~~The problem revealed that p~~Patients feared attending the ED and felt vulnerable while in the ED for a number of reasons,—which This appeared to be a well-defined and solvable problem. ~~Once this tame problem was revealed, a possible solution was developed in co-production with patients.~~ The solution proposed was an Asthma Patient Passport (APP), which increased patient's confidence in theirpatient's ability to communicate their needs while in severe distress ~~by communicating their needs~~ The APP decreased (from twelve to five steps) the work patients had to do to achieve care. The APP project is currently being evaluated.

Practical implications: The APP should be offered to all people with severe asthma.

Originality/Value: By revisiting systems thinking and identifying problems, a solution was identifiedpossible. Although methods such as soft systems methodology have limitations when used ~~to~~ in 'wicked' (difficult or impossible to resolve) problems, such methods still

Comment [KH1]: Format corrected throughout; please do not change unless asked. Redundancy removed; wordcount reduced from 4030 to 3677

Comment [J2]: Thank you.

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Comment [KH5]: I'm guessing these are 'patients'. Are they happy to be outed?

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~~appear to~~ have merit in tame problems and ~~were applicable could be used~~ in ~~these~~ ~~case circumstances~~ to fully understand ~~the issues~~ ~~problems~~ and design practical solutions.

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Severe asthma patients were excluded from the original NHS Improvement work because they had different needs. Asthma is known as severe when a patient has a confirmed asthma diagnosis and ongoing symptoms despite adherence to treatment. It is recognised by one or more near-fatal asthma episodes; e.g., previous ventilation or respiratory acidosis, previous admission for asthma especially in the last year, requiring three or more asthma medication classes, heavy β_2 agonist use and repeated ED attendances for asthma care (British Thoracic Society, 2014). Severe asthma cases in the Trust are fully medically optimised and are supported by specialist asthma clinic staff. They all have bespoke asthma action plans, which are drawn up between themselves and the asthma clinical nurse specialist (CNS). The plan outlines how to titrate asthma treatments according to symptom and when to access medical assistance.

To evaluate these plans locally, interviews were conducted with service users. The interviews showed that patients valued the asthma action plan, but there was usually awkwardness around when and how to access emergency medical care. Exploration revealed that patients were putting their lives at risk because they had such a difficult time in ED and they preferred to stay at home and take high bronchodilator therapeutic doses. Patients said they avoided the ED, even in extreme respiratory distress, for several reasons:

- Feeling vulnerable or fear in the ED when they are least able to talk; i.e., when unable to say what they needed, which caused more distress.

Comment [JH15]: Format corrected throughout.

Comment [J16]: Thank you.

- They are asked the same questions many times and felt that they are not always listened to.
- Treatment isn't always escalated as quickly as they felt it needed to be.
- Patients had no choice about which ED the ambulance service staff took them; consequently, they elected to use either their own or public transport even when in severe respiratory distress.

Understanding this experience structured the problem and therefore this study. A soft systems thinking approach (Checkland, 2001) was taken to identify the specific problem and then construct a satisfactory and sustainable solution. Soft Systems Methodology (SSM) was chosen as it helps conceptualise, define and address problems and is particularly useful in people oriented systems, and allows issues to be considered from a more holistic whole systems perspective. Once possible solutions had been identified a plan, do, study, act (PDSA) cycle was used as a quality improvement approach (Langley *et al.*, 2009).

Methods

To understand the problem more fully, ~~soft system methodology (SSM)~~ was applied (Langley *et al.*, 2009; Checkland 1981). An overview can be seen in Figure 1. Soft system methodology originated in systems engineering and has been in use for over thirty years and attempts to foster learning and understanding of a problem situation through a group of stakeholders instead of attempting to solve a pre-determined problem. Initially, meetings and interviews are held in order to obtain an understanding of the problem situation and identify relevant systems after which conceptual models of the systems are generated. These models are then used as a basis for debate and can lead to feasible and desirable changes which can be actioned. Whilst it is commonly considered that general systems thinking has not delivered the anticipated changes in healthcare, applying systems thinking to tame problems has been beneficial in many areas (Checkland, 2001)

Figure 1 here.

Results

Identifying the problem locally

Step 1: Situation considered problematic

From local interviews, patients with severe asthma did not appear to be seeking emergency medical help when they needed to. This behaviour is associated with avoidable harm/death (Levy *et al.*, 2014). The NRAD report into avoidable asthma deaths (British Thoracic Society, 2014) states that 45% (87) of the 195 people who died did so without seeking medical help or before emergency medical care could be provided. Previous hospital admission for asthma occurred in 47% (90 of 190). Nineteen (10%) of the 195 died, within 28 days of discharge from hospital after asthma treatment. At least 40 (21%) who died had attended an ED with asthma at least once in the previous year and 23 had attended twice or more. Thirty-nine percent appeared to have severe asthma. The NRAD report (British Thoracic Society, 2014) and local patient experience work underlined having a personal asthma action plan. During the co-creating an asthma action plan process, the asthma CNS often felt resistance from severe asthma patients around when and how to access emergency medical care, which needed exploring. The asthma CNS felt that patients were putting their lives at risk because they had such a difficult time in the ED. Owing to the difficult time in the ED, they preferred to stay at home and take high doses of bronchodilator therapy (Asthma UK, 2004). The reasons behind this decision had not been considered systematically within this service. Trust staff currently care for around 800 severe asthma patients per year.

Comment [J17]: Abbreviated already above.

Comment [KH18]: Please don't start sentences with abbreviations or numbers—corrected throughout.

Comment [J19]: Thank you.

Comment [J20]: Added at the request of Reviewer 1 'Clarity is required in explaining the methodology part'.

Comment [KH21]: Why appeared? Were the case-notes too vague?

Comment [J22]: Of 195 patients who died 155 patients had the severity of their asthma estimated from the information available. Patients were divided into three categories, 'severe', 'mild' and 'moderate' with 39% of the 155 being classed as 'severe'.
The report states that 'It is likely that many patients who were treated as having mild or moderate asthma had poorly controlled undertreated asthma, rather than truly mild or moderate disease.' which is presumably why it states 'appeared'.

Comment [KH23]: Anthropomorphising corrected throughout.

Comment [J24]: Thank you.

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Defining the problem revealed that it had characterised a tame problem (Rittel and Webber, 1973) in that the problem can be articulated with a clearly desired outcome - that distressed patients feel able to go to the ED. The problem can be stated as a gap between *what is* and *what ought* to be – the latter agreed by professionals and patients.

Step2: Problem situation described

Soft system methods help to formulate and structure thinking about problems in complex human situations by applying systems thinking about things that happen in the real world. It is most usefully carried out by the people immersed in the problem situation, in this case, people with severe asthma and the asthma CNS who provides expert help to guide and facilitate the process. The asthma CNS facilitated a focus group with the patients and the allergy CNS to gain a situational insight. The findings from the group echoed the asthma plan evaluation themes:

- Feeling vulnerable and afraid
- Asked the same questions repeatedly when least able to talk
- Unable to say what they need when least able to talk
- Feeling that they are not always listened to
- Life-saving treatments aren't always escalated as quickly as necessary
- Healthcare staff do not always appreciate the attack's severity
- Individual fears; i.e., being left alone in a cubicle when they think they are dying

Owing to the initial meeting, process mapping was introduced to explore the issues (Newell *et al.*, 2014). The process mapping revealed that twelve separate actions were required to gain treatment when self-presenting to the ED and thirteen if brought by ambulance and these are listed in Appendix 1 (Newell *et al.*, 2015)

Step 3: Root definitions

It was agreed by the co-production group that 'something needed to be done', thus a project team was established to set out a shared purpose and vision. The project's aim was that patients with severe asthma would seek emergency help appropriately. A further aim objective was that when patients with asthma went to the ED, they should feel that they were being taken seriously and be able to work with staff to achieve the best outcomes. Returning to SSM to help achieve these aims this objective, several questions are posed.

1. What the system will do?
2. How it is done?
3. Why it is being done (long term aim)?

Underpinning this is a transformation process in which something is changed or transformed into something else, which revealed the study question/system requirement: *A system to encourage people with 'severe asthma to go to the ED when they need to for the right treatment, in the right place, at the right time without fear' (outcomes).* Once the problem has been defined, the SSM CATWOE checklist (Checkland, 2001) was used to solve problem:

Customers - it was the asthma CNS's duty to listen carefully to what patients with severe asthma had to say about seeking emergency help and contribute to enabling ED and London Ambulance Service (LAS) staff to understand patients' needs.

Actors - those involved in the situation and in partnership with them, to act on what had been discussed. How might they react? What is ~~is~~ their stake in improving the situation?

Comment [KH25]: Introduced to what/where?

Comment [KH26]: List the 12 and 13 in Appendix 1?

Comment [J27]: All stages for ambulance and ED presentation have been added in Appendix 1 both with and without the APP.

Comment [JH28]: 2020 in your reference.

Comment [J29]: Apologies that was an error it should be 2015.

Comment [KH30]: Reads like an aim not an objective.

Comment [J31]: This has been changed to 'aim' as suggested.

Comment [KH32]: These aims?

Comment [J33]: This has been changed as suggested.

Comment [KH34]: Not a question. Is 'What will the system do?' better.

Comment [J35]: This change is fine.

Comment [KH36]: Unclear, why is outcome bracketed?

Comment [J37]: Outcome has been removed as unnecessary.

Comment [KH38]: Doesn't make sense

Comment [J39]: Clarified in the text.

Transformation - so that the patient group would change their behaviour and go to ED when they needed to. Staff reacted in a way that reassured and met patients' needs rather than increase distress and fear.

Weltanschauung (this is the right thing to do) - because not to do so put patients at risk - they say they are already at risk and want to do something about it.

Owners of the process - all the stakeholders and included: patients with severe asthma, ED clinical staff, ED reception staff, London Ambulance Service (LAS) staff, asthma Professor, Patient Experience Team, Communications and Patient Publications.

Environmental constraints - NRAD (British Thoracic Society, 2014) describes how people with asthma were needlessly dying because patients failed to recognise the asthma attack's severity, healthcare staff's failure to recognise attack severity and inappropriate or under-treatment. It was fundamental that any plan took these constraints into account.

Step 4: Conceptual models of systems described in root definitions

Drawing out a conceptual model highlights the many reasons why the patient group weren't going to ED without losing sight of how component parts fit together (Figure 2).

Figure 2 here

Designing the intervention - the Asthma Patient Passport (APP)

Patients aren't necessarily local to the Trust and therefore need to use different EDs and so a local arrangement wasn't an obvious solution. Another option was to have a national database of people with severe difficult to manage asthma so that the ambulance service and the various UK EDs had all the necessary information about the patient, but this was impractical. Establishing such a system would be resource intensive because there is no common information technology infrastructure in the UK. Other long-term condition groups, such as people with learning difficulties and mental health problems and palliative care needs, were already using a Patient Passport as a collaborative communication tool and this had been found to be helpful in accessing services (Abbot *et al.*, 2015). A local Chronic Obstructive Pulmonary Disease (COPD) Passport was being used and it was felt that the design had been well evaluated. The COPD Passport is a credit card sized z-card (a z-card is a piece of paper with a number of panels of information on it that folds down into a credit-card sized card that can easily be stored in a wallet or purse) and ~~is~~ simply records relevant demographic and clinical information. Where the Asthma Patient Passport (APP) would differ from the COPD Passport is that it would be designed by patients for patients and would also consider ambulance service and the ED staff needs. The other important factor was the decision to use the model for improvement as a way for implementing health service change (NHS Institute for Improvement, 2014). Every time a patient used the APP, their experience was fed back by the patient or other user (e.g., LAS) to the group and any suggestions were incorporated into the APP:

- Putting the emergency information at the beginning of the document
- Adding a box for the Asthma Physician's signature to lend credibility
- Changing the word 'severe' to 'brittle' as it is more commonly understood in those who do not specialise in asthma treatment
- Having an explicit statement about what to do if arterial blood gases (ABG) are needed (as ED staff felt that gaining permission to undertake ABG's can be challenging at times)
- Adding a review date
- Having a pre-hospital treatment section for the ambulance journey

Comment [KH40]: First use, in full please.

Comment [J41]: Full text added for LAS as requested.

Comment [KH42]: Explain in brackets.

Comment [J43]: Explained as requested for Z-cards

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- Highlighting and dating previous ITU/HDU admissions
- Adding a triggers section
- Designing watermarks that provide subliminal awareness information on crucial safety factor such as the silent asthmatic

These suggestions won commitment from various health staff groups and patients.

Step 5: Comparing models with the real world

The problem examined was APP development and to compare this model with the real world. The APP made the patient journey through the ED more efficient. Patients brought in by ambulance went through a 13-stage process before the APP was introduced. With the APP in place, there are now only nine steps. Self-presenting patients also went through 12 steps before the APP was introduced and five afterwards (see Appendix 1). The APP streamlined the process by improving communication allowing improved access and flow through emergency care. This reduced delays and ensuring treatment is individualised and right the first time, thereby improving quality and possibly lowering costs (Newell *et al.*, 2015).

Comment [J44]: Steps added in the process maps in Appendix 1

Step 6: Changes - systematically desirable, culturally feasible?
Does the solution work?

The APP was developed and piloted for three months with 15 patients. During this period, it was used 15 times by seven patients. After a positive feedback and some minor alterations based on the feedback, the APP was trialled for one year. During this time, regular meetings and consultations were held with partners (patients, specialist nurses, ED and LAS staff and the medical consultant) who were consulted extensively throughout the trial period using this approach. Finally, an APP document (Figure 3) was devised that provided this patient group with the confidence to attend ED when appropriate, and assisted healthcare staff in treating them (Newell *et al.*, 2014).

Figure 3 here

Is it worthwhile?

The APP addressed four key areas most important to patients: (i) being left alone; (ii) being unable to communicate needs; (iii) feeling frustrated at not being listened to; (iv) being asked the assessment questions repeatedly at a time when they are too breathless to talk) and in doing so improving; treatment timeliness, decision making, patient experience (the APP's original aims) (Newell *et al.*, 2014). The APP also appeared to meet a London Ambulance Service staff need, captured in this comment ... *the patient doesn't have the pressure of having to give their story to the ambulance crew (which) takes the pressure out of the situation.*

Does the solution achieve its goals?

As patients have a better experience, they report that they are more likely to access emergency services in a timely manner and receive correct treatment (Newell *et al.*, 2014). The APP now features regularly in clinical practice at the London NHS Foundation trust we studied.

Step 7: Action to improve the problem situation

The action taken was to implement the APP for patients with severe asthma at one large London NHS Foundation trust. There are plans to undertake a multi-centre study using a mixed-methods approach, which will include an impact evaluation.

Discussion

There is breadth and value in the SSM approach and the PDSA cycle in tame (well-defined) problems. Patient passports are common in other long term conditions (National Quality Forum, 2015). The APP was specifically co-designed to meet an expressed need and it was the patients and asthma CNS that drove the development process. The core group included patients, asthma and allergy CNSs, and it was the collaborative approach adopted by patients and wider team (including ambulance and ED staff) that helped to get it right. Inextricably connected with this was learning by doing so that every time a patient used the APP, it was discussed with the asthma CNS and the APP was improved. The tame problem was that severe asthma patients weren't accessing emergency healthcare when they needed to. The patient's perspective is highly relevant to efforts to improve healthcare quality and effectiveness (Frew *et al.*, 2011) and because all parties were involved in the creation process, all parties benefited – a win, win, win' patients, clinicians and healthcare system. The patients feel more secure and are more likely to go to the ED and get the right treatment, in the right place, at the right time. Healthcare staff have all the necessary information, which is individualised and easy to follow. The healthcare provider benefits because the process is leaner and outcomes are improved, which indicates a cost saving (was not assessed during the study). The APP implementation is undergoing evaluation.

Conclusion

Systems thinking and SSM have limited applicability in the NHS because the methods have been applied to wicked (complex and unanswered) problems. Our work shows that there is some benefit to be gained from SSM application in tame, well defined problems to help understand and solve the problem.

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- ~~Asthma UK (2014), 'Asthma Facts and FAQ'. <<https://www.asthma.org.uk/about/media/facts-and-statistics/>>, accessed December 2015.~~
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- ~~Checkland, P.B. (2001), 'Soft Systems Methodology' in 'Rational Analysis for a Problematic World Revisited', eds. J. Rosenhead and J. Mingers, J. Wiley, Chichester, Sussex.~~

Comment [KH45]: References aren't formatted correctly; please mimic the blue examples precisely.

Comment [J46]: Revised formatted references below.

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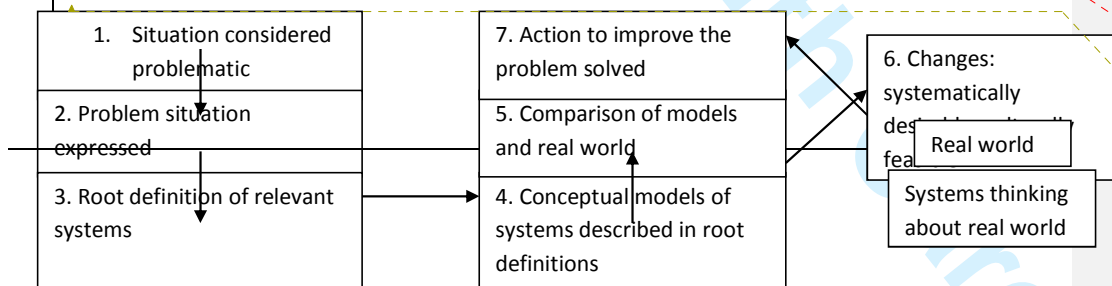
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Figure 1: Soft systems methodology - Checkland's 7 stage overview



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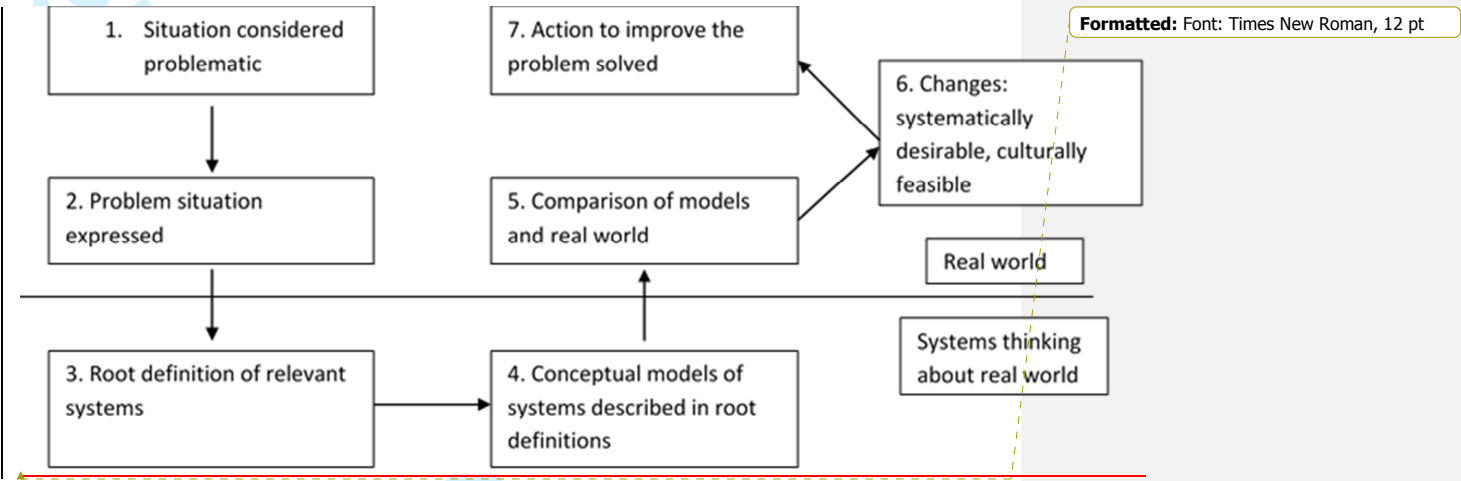
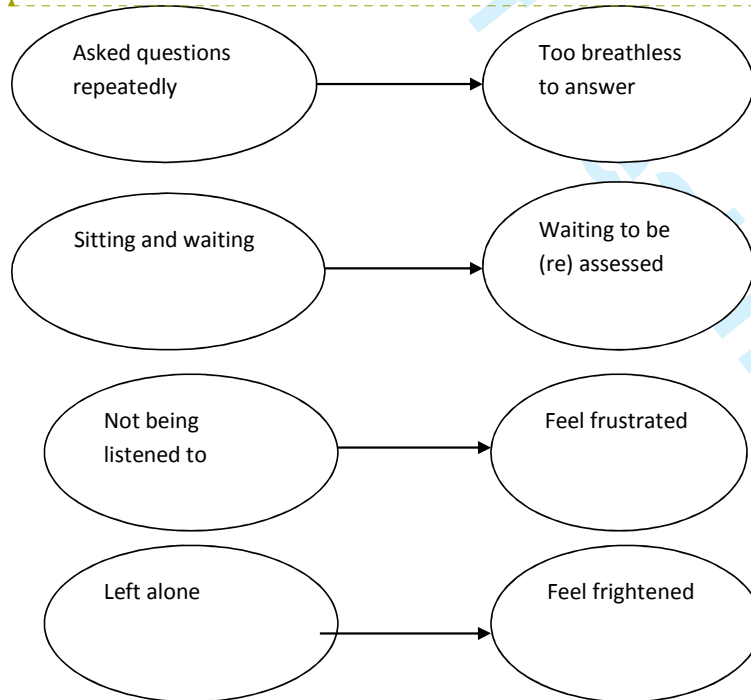
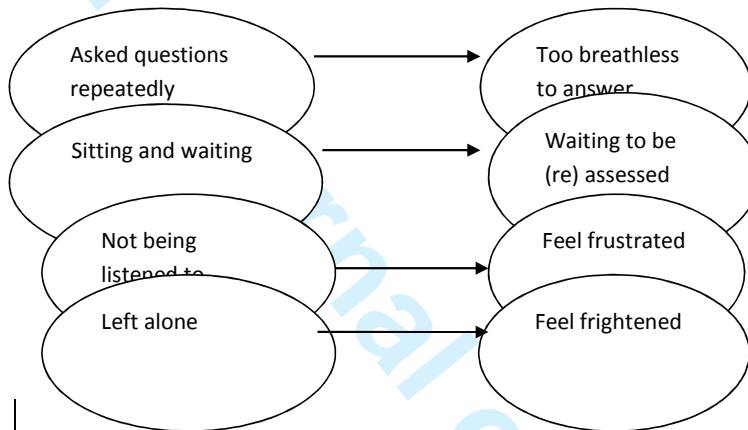


Figure 2: Reasons why severe asthma patients were not going to ED when they needed to.

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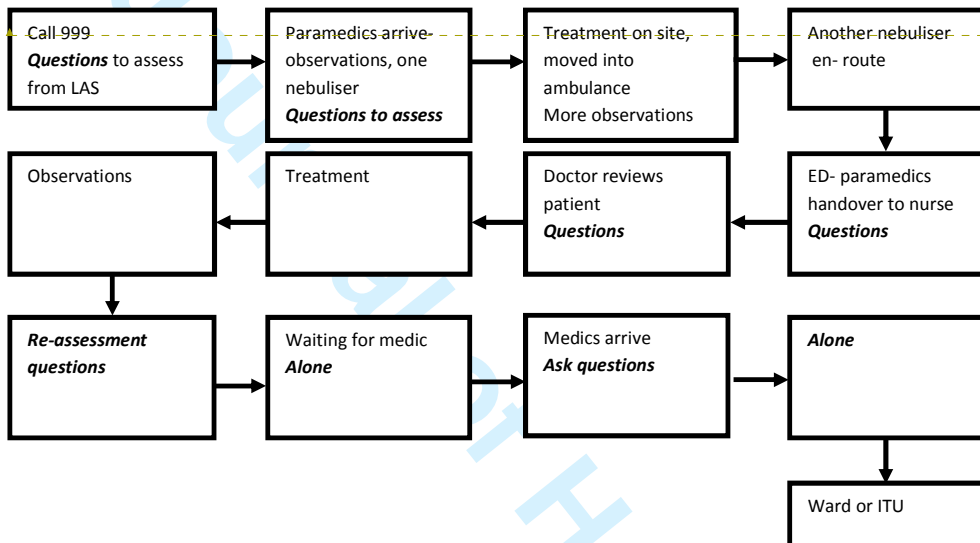
The silent asthmatic is an asthmatic in trouble

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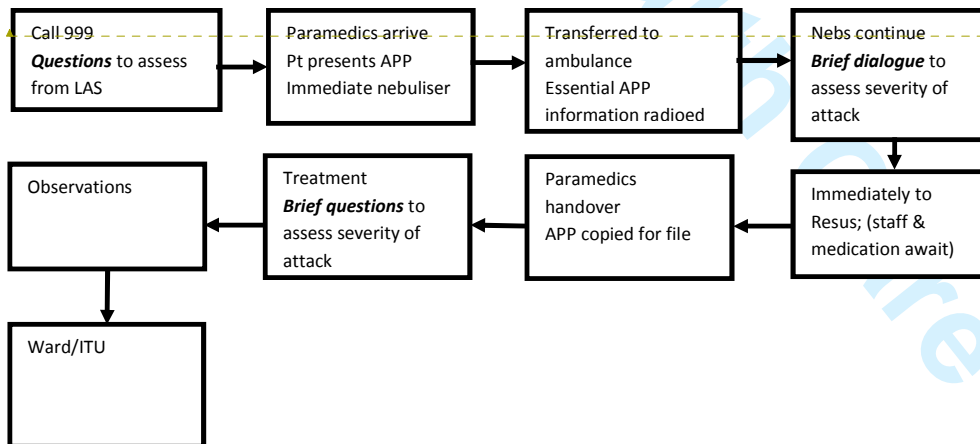
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Appendix 1:**Ambulance process mapping before the introduction of the APP**

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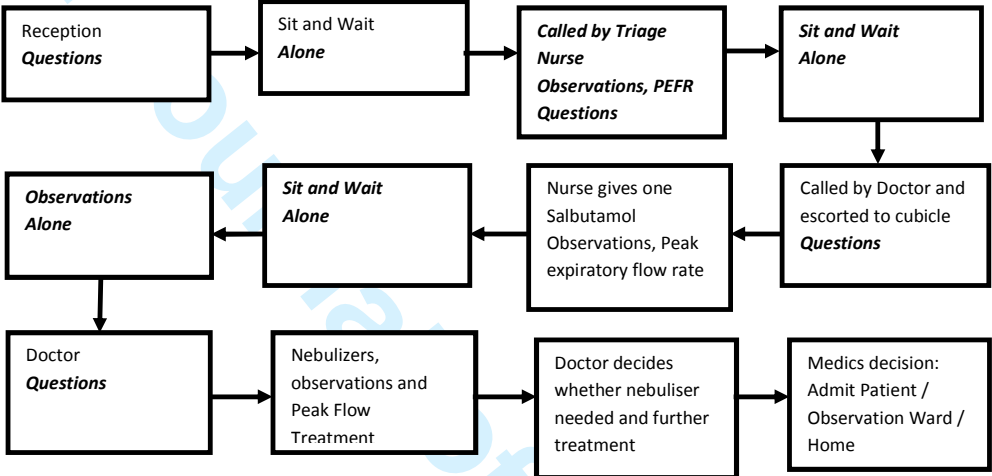
Ambulance process mapping after the introduction of the APP

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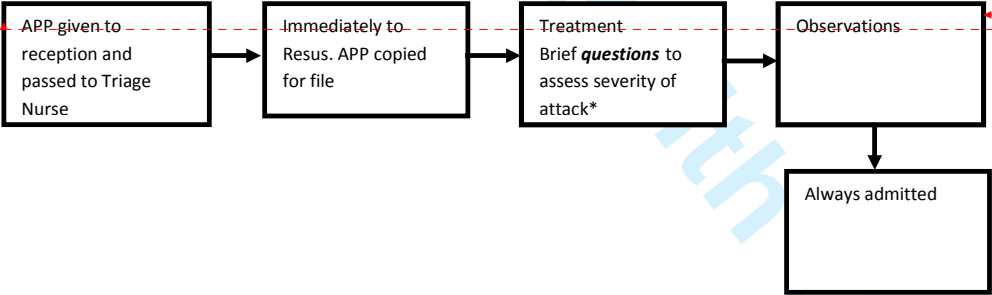
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Self-presenting at the Emergency Department process mapping before the APP



Self-presenting at the Emergency Department process mapping after the introduction of the APP



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